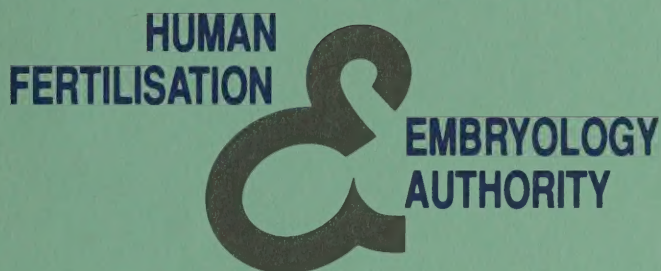


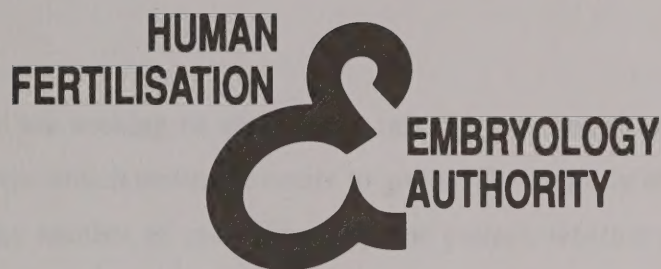
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**THE PUBLICATION OF
CENTRES' SUCCESS RATES FOR
IN VITRO FERTILISATION AND
DONOR INSEMINATION
CONSULTATION DOCUMENT**



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**THE PUBLICATION OF
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DONOR INSEMINATION
CONSULTATION DOCUMENT**

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HUMAN FERTILISATION AND EMBRYOLOGY AUTHORITY

CONSULTATION DOCUMENT

THE PUBLICATION OF CENTRES' SUCCESS RATES FOR IVF AND DI

Introduction

1. Patients who are seeking or considering infertility treatment are often faced with a difficult decision about which treatment centre to go to. The majority of treatment cycles are unsuccessful, and the number of cycles that any one patient, whether private or NHS, will have is usually very limited.

2. In order to make this decision people need information. They need information that is relevant, meaningful, and reliable. They need information that will put them in a position to make a decision which is right for them. While certain information is available from GPs, licensed centres, support groups, and a few other sources, the Authority recognises that it, too, has a responsibility to provide information that will be helpful to those seeking treatment.

3. Section 8 of the Human Fertilisation and Embryology Act 1990 states that the Authority must "provide, to such extent as it considers appropriate, advice and information for persons.... who are receiving treatment services."

4. The Authority already publishes a range of information for patients and prospective patients. This includes:

- * leaflets on:

- treatment clinic: questions to ask
- egg donation
- sperm and egg donors and the law
- *in vitro* fertilisation
- the role of the HFEA

- * list of licensed centres

- * Code of Practice

- * annual reports

5. The one item of information which is most often sought by patients, but which the Authority has not so far been able to provide, is the success rates for *in vitro* fertilisation (IVF) and donor insemination (DI) in individual centres. It is not only patients who seek this information. The Authority is also regularly approached by NHS purchasing authorities for information about centres from whom they are considering purchasing treatments for their patients. Success rates are also of interest to the media, to GPs, to professional bodies and to the public in general.

6. This paper explains why the Authority intends to publish individual centres' success rates, and raises questions of the form and context in which they should be published. The paper is divided into four sections dealing with the publication of success rates as a question of principle; the context of information on success rates; ways of producing success rates; and, finally, a summary of the Authority's position and the issues on which comments are invited. A number of Annexes and glossary are also included.

1. The Publication of Success Rates

7. In the Authority's last annual report, the Chairman stated that:

"We are considering the feasibility of publishing success rates for individual centres. This is perhaps the most frequent request we get from patients who are about to choose a centre. However, producing success rates is not the straightforward task it might first appear. Success rates depend on a number of factors, including the age of the woman being treated and the reasons for infertility. A set of reference data which allows for valid comparison between centres therefore needs to be identified. Our objective is to provide people with information which is both meaningful to them and fair to centres. We are determined to find a solution which is widely acceptable in the coming year."

8. In recent months the Authority has been looking both at the question of publication of success rates in general, and at detailed options for publishing this information. A highly important factor in the Authority's consideration has been the volume of requests that it receives for this type of information. At the same time, the Authority has been mindful of

the momentum that is gathering for public bodies to provide relevant information to the users of various services. It has also taken account of the fact that centres have always provided information about their success rates but that the data across centres is often inconsistent. The problems this creates for patients and purchasers are all the more difficult because of the large and growing number of licensed centres in the UK which need to be contacted individually to obtain information.

9. The Authority also considered what effect its publication of success rates might have on individual centres. There is an argument that centres with lower success rates might become demoralised and find themselves on a downward spiral which might ultimately lead to closure. However, this is set against the argument which says that improved awareness of the performance of others should lead centres into changing practice to improve performance to the level of the best. In view of the fact that centres already give out their own success rates, the Authority concluded that the main effect of publishing success rates would be the introduction of consistency in the presentation of the data.

10. A further argument against publication has been that the data will not take account of the position of centres which are conducting clinical research trials in an effort to improve outcomes. The Authority recognises that this needs to be considered and would be interested to learn from current experience how centres deal with this in presenting their own success rates to patients.

11. As a matter of principle it is difficult to argue that individuals should not be given information that they need if that information is available, informative, useful, and not harmful to any other person. Many patients want this information, and it would also clearly be of considerable value to those who make decisions about purchasing treatment on behalf of NHS patients. The Authority's view, having balanced the arguments, is that information should be given; the main question is the context and format in which it should be given.

12. There are clear drawbacks in the provision of raw data on live birth rates for infertility treatment, not least because these do not reflect the variety of circumstances that patients face and the wide variability of outcomes in these different circumstances. For a large minority

of patients "raw" success rates will be less than helpful, and possibly unfair to a number of centres.

13. However, the present situation is one in which patients often receive details of success rates from individual centres. These are either raw data, and not therefore comparable, or they are broken down into more detailed figures, but in different ways in different centres. This also makes them not comparable.

14. The Authority has therefore examined a number of ways of presenting success rates which would overcome these difficulties, either by presenting a range of rates, or by modelling the data according to known factors, and certainly by placing them in the context of other issues which need to be considered when approaching a centre for treatment. These are considered in more detail in sections 2 and 3 of this paper and in its annexes.

15. The Authority's intention is to find a format for presenting success rates which will make them meaningful for individuals, whilst avoiding known difficulties. At present it favours the statistical modelling method described below. Such rates would be published not in the form of a table, but in relation to each individual centre, and in the context of a wide range of other general information which is important when selecting a centre.

Are there reasons why the Authority should not provide information for prospective patients about centres' success rates in the context of other general information which is important in selecting a centre?

2. The Context of Information on Success Rates

16. When considering whether to proceed with IVF or DI treatment, and before deciding on which centre to attend, patients do need to be informed about what they should expect and what further information they can reasonably demand. There are many factors to consider, and the success rates of the treatments in general and of the centres in particular is only one of these factors.

17. The Authority proposes to publish a booklet, which will be widely available, to help patients focus on the questions that they need to address before deciding how to proceed. This booklet will contain information about each centre, including its success rates, as well as general information about the kind of questions that patients may wish to address. It will be based on the current HFEA booklet "Treatment clinic: questions to ask".

18. Annex B contains an illustration of the kind of information which the Authority intends to provide in this booklet. It includes such considerations as:

- location
- cost
- services offered
- investigations carried out
- specialisms
- age and other restrictions
- success rates
- availability of counselling

19. Amongst the important issues that it must cover are the fact that the success rate data do not represent the likelihood of success for any particular couple; that success rates are indicative of performance but are only one of a number of factors to be considered; and that the chances of success of any particular couple can only be assessed in consultation with a specialist.

Comments are invited on the issues raised in the draft booklet at Annex B. Is the booklet useful and clear? Are there other points which should be covered? What particular details should be included in the booklet?

3. Ways of Publishing Success Rates

20. In publishing the success rate of each centre the Authority needs to be confident that the figures which it publishes are accurate and informative, and that they are not unfair to centres or harmful to patients. In showing the figure alongside a range of other information

the Authority recognises not only that other issues need to be considered, but also that the way in which they are published must be carefully considered in terms of the different factors which can actually affect the outcome of treatment.

21. The Authority has looked at three methods of presenting success rates. These are "raw" success rates, "gold standard" success rates, and statistically modelled success rates.

22. **Raw success rates** are the simple results of all treatments in terms of live births per treatment cycle commenced. While these results would show the actual activity of each centre, they are commonly thought to be misleading. This is because different centres treat different couples with different types of problem. For example, one IVF centre might treat a large proportion of relatively young women whose partners are fertile, whereas another centre might treat more older women or more subfertile men. In this case one would expect the second centre to have lower results than the first, and it would be misleading to the patient and unfair to the centre to suggest that the centre is less successful simply because it achieves a lower live birth rate.

23. **Gold standard success rates** are based on the notion that if a group of patients in a particular category is identified in each centre, then the centres' results for those patients can be compared. Thus one might say that results based on IVF treatments for women under 38 with damaged fallopian tubes and no male factor infertility could be compared. This is the group which doctors often choose as presenting the classical indication for using IVF. However, the Authority's data shows that for many centres the number of patients who fall into any gold standard category is too small for comparisons to be usefully made. If the category is widened to increase the numbers, the value of the gold standard comparison is diminished.

24. The Authority's database shows that the results for over half the centres would be unreliable on any gold standard analysis because of the small number of treatments falling into any useful category.

25. **Statistically modelled success rates** provide a method of showing each centre's results having taken account of the different types of patient it has treated, allowing more valid comparisons to be made. This method works by using the HFEA database to calculate the likely effect of the main factors which can influence outcomes, such as patient age, type of infertility, previous pregnancies, etc. For each centre its results are adjusted to take account of the profiles of the patients it has actually treated.

26. To perform these calculations the Authority has a validated database that extends at present to over 20,000 IVF cycles and almost 40,000 DI cycles. By mid-1995 these figures will be closer to 40,000 and 60,000 respectively. This means that the power and reliability of this method as an indicator of the effect on outcome of the different factors is great and will increase over time.

27. A more detailed explanation of this method is provided at Annex A. It takes full account of the major factors affecting outcome, and, with very few exceptions, even these major factors together do not affect any centre's raw success rates by more than 2%. It is unlikely that an individual centre's patient population would present with other minor factors to the extent that they would have a significant impact on their overall success rate.

28. Annex C shows data relating to several anonymised centres. Each entry illustrates the way in which the success rate data would be shown for each centre as part of a more general set of information which patients may need. The success rate for the centre is shown as the "adjusted live birth rate" and this is the figure that is arrived at after the statistical calculation has been carried out.

29. As with any statistical analysis, such results are more reliable when they are based on larger numbers of treatments. Thus the success rate figure is likely to be more accurate in large centres than in small ones. However, the Authority is also able to calculate the possible range for each centre's success rate, and this is given at the foot of each centre entry in Annex C. No success rate would be shown for centres which have performed less than 50 cycles during the 1-year reporting period as the reliability of the figure decreases rapidly below this number of treatment cycles.

Comments are invited on the options described above for publishing centres' success rates. Reasons why the method described in Annex A might not be appropriate would be particularly welcome, together with comments on:

- i. factors affecting outcome which are used or not used in the model; and**
- ii. the method of presenting information on each centre.**

4. Summary

30. The Authority's position on the publication of success rates could be summarised as follows:

- i. that it is right to provide information that may help people unless it can be shown to be unfair to centres or harmful to patients;
- ii. that of the options considered, statistically modelled success rates provide the best and most reliable data on success rates;
- iii. that publication of such success rates would be better and more reliable than the present position in which each centre presents raw or other non-comparable data;
- iv. that it proposes to publish such data subject to any major drawback that is not currently apparent;
- v. that success rates should only be published in the context of a wider set of information that patients should take account of when considering IVF or DI treatment; and
- vi. that the success rates should be accompanied by a narrative which clearly indicates that the modelled success rates are indicative of a centre's overall performance. They do not show any particular couple's chances of success as this can be assessed only in consultation with a specialist.

31. The Authority invites comments on the points and questions raised in this paper, including:

1. Are there reasons why the Authority should not provide information for prospective patients about centres' success rates in the context of other general information which is important in selecting a centre?
2. Is the draft booklet at Annex B useful and clear? Are there other issues which should be covered? What particular details should be included in the booklet?
3. The options described above for publishing centres' success rates, in particular, reasons why the method described in Annex A might not be appropriate, together with comments on:
 - i. factors affecting outcome which are used or not used in the model; and
 - ii. the method of presenting information on each centre.

Any other comments would also be welcome. Responses should be addressed to:

**Bill Parslow
HFEA
Paxton House
30 Artillery Lane
London E1 7LS**

and should reach the Authority not later than 31 March 1995.

A METHOD FOR COMPARING RESULTS FROM INFERTILITY CENTRES: IVF AND DI

Introduction

1. It is unfair to quote the overall live birth rates for each centre without making some allowances for the fact that different centres will treat different types of women. For instance some centres treat, on average, older woman than other centres. A well known mathematical method, called indirect standardisation, has been employed which will adjust the raw percentages to allow for the different composition of the groups of patients attending each centre. This annex outlines the factors which, from analysis of HFEA data, appear to affect live birth rates and are used to adjust the raw figures for IVF and DI respectively.

The method used: indirect standardisation

2. Indirect standardisation is a well known statistical method for comparing different groups by compensating for differences in their composition. The above factors have been the most predictive as to the probability of a couple having a live birth either by IVF or DI, when the many thousands of treatments collected by the Authority are analysed. Centres should not be penalised for treating women with a worse prognosis due to these factors. For each centre the method calculates the total number of expected live births, for that particular mix of patients. This is compared with the actual number of live births that did occur. From these two figures an adjusted birth rate is calculated for each centre which allows valid comparisons to be made between centres.

Factors affecting live birth rates: IVF

3. The age of the mother, the type of treatment (for example, using fresh or frozen embryos), whether the woman has had previous live births, previous IVF pregnancies or previous unsuccessful IVF treatment will affect the woman's chances of having a live birth. The presence of any male factors for infertility will also affect the success rates. These are considered in detail below.

The age of the mother

4. This is highly significant in predicting the chance of a successful live birth. Figure 1 shows that the live birth rate is highest for a woman between the ages of 23-27 and falls rapidly after the age of 38. Figure 1 indicates the success rates for all women of different ages. Therefore a centre treating only women of 40 would expect to have a live birth rate of only 3.4% whereas a centre treating 25-30 year old women would expect to have a success rate nearer to 12%.

Male reasons for infertility and use of donated sperm

5. All reasons for male infertility are assumed to have a similar effect on the chance of the woman having a live birth. Analysing the data has indicated that for women using their partner's sperm the success rates are lower if a male factor is present. If a male factor is present, women using donated sperm have a higher success rate than those using their partner's sperm.

Fresh embryos and unstimulated cycles

6. If fresh embryos are used the odds of having a live birth are much higher in stimulated cycles than unstimulated cycles.

Frozen-thawed embryos

7. If frozen-thawed embryos are used the odds of having a live birth are reduced compared to using fresh embryos and a stimulated cycle, but are higher than using fresh embryos in an unstimulated cycle.

Previous live births

8. If a woman has had previous live births her odds of having a further live birth are 20% higher than a woman who has not.

Previous IVF treatments

9. If a woman has had previous IVF treatment which resulted in a pregnancy then her odds of having a live birth are 13% greater than a woman who has not. Women who have

had 1,2,3 or 4 or more IVF treatments that have not resulted in a pregnancy are 10%, 14%, 25% and 41%, respectively, less likely to have a live birth than women having IVF treatment for the first time.

Stimulated/unstimulated IVF treatments

10. Success rates are higher for stimulated cycles than unstimulated. Therefore a centre carrying out many unstimulated cycles will have lower overall live birth rates. The method adjusts for this so that these centres will have their overall rates increased. However, it might be argued that the women is receiving less effective treatment if she does not have a stimulated cycle.

Factors that affect live birth rates for IVF but are not taken into account by the method

Number of embryos transferred

11. This is not taken into account when producing the success rate and comment is invited as to whether it should be. A policy of transferring only two embryos for suitable women reduces the incidence of multiple pregnancy and the risks associated with this. However, it may result in fewer live births per treatment than if three embryos were transferred.

Donated gametes

12. Women being treated with donated embryos or donated eggs are excluded from the analysis, although numbers are currently small. Success rates with donated eggs and embryos are higher than with women using their own eggs and an increase in the number of such treatments would distort the overall success rate.

The Results: IVF

13. Annex C gives examples of a set of tables of comparative success rates and other information that would be included in an HFEA booklet. In general, the raw live birth rates are not greatly affected by the adjustment: the centres with the highest rates remain highest. In 1992 there were only 3 centres where the adjusted rate differed from the raw rate for women under 38 by over 2%.

Factors affecting live birth rates: DI

14. The chances of having a live birth will be affected by the age of the mother, the presence of any female factors for infertility, whether she has had previous live births, whether she has had previous DI pregnancies or whether she has had previous unsuccessful DI treatment.

The age of the mother

15. As with IVF, this is highly significant in predicting the chance of a successful live birth. Figure 2 shows that the live birth rate is fairly level for women between the ages of 23-32 and falls rapidly after the age of 38. A centre treating only women of 40 would expect to have a live birth rate of only 3% whereas a centre treating only 25-30 year old women would be expected to have a success rate nearer to 6%.

The presence of female reasons for infertility

16. A small number of treatments cited female reasons for DI treatment. The success rate was 45% higher than for couples for whom no female reason was cited.

The presence of male reasons for infertility

17. The presence of male or unknown reasons for infertility did not affect chances of success.

Stimulated cycles

18. Overall the success rate from using stimulated cycles of DI was not significantly greater than the success rate using unstimulated DI.

Previous live births

19. If a woman has had previous live births her odds of having a further live birth are 16% higher than a woman who has not.

Previous DI treatments

20. If a woman has had previous DI treatment which resulted in a pregnancy then her odds of having a live birth are 43% greater than a woman who has not. Women who have had

1,2,3 or 4 or more DI treatments that have not resulted in a pregnancy are progressively less likely to have a live birth than women having DI treatment for the first time (their chances are about 97% that of the previous time).

The Results-DI

21. Annex C gives examples of a set of tables of comparative success rates and other information that would be included in an HFEA booklet. As with IVF live birth rates, the results for large centres are not greatly affected by the model because they tend to treat a balanced cross-section of patients. For some small centres there are wider variations.

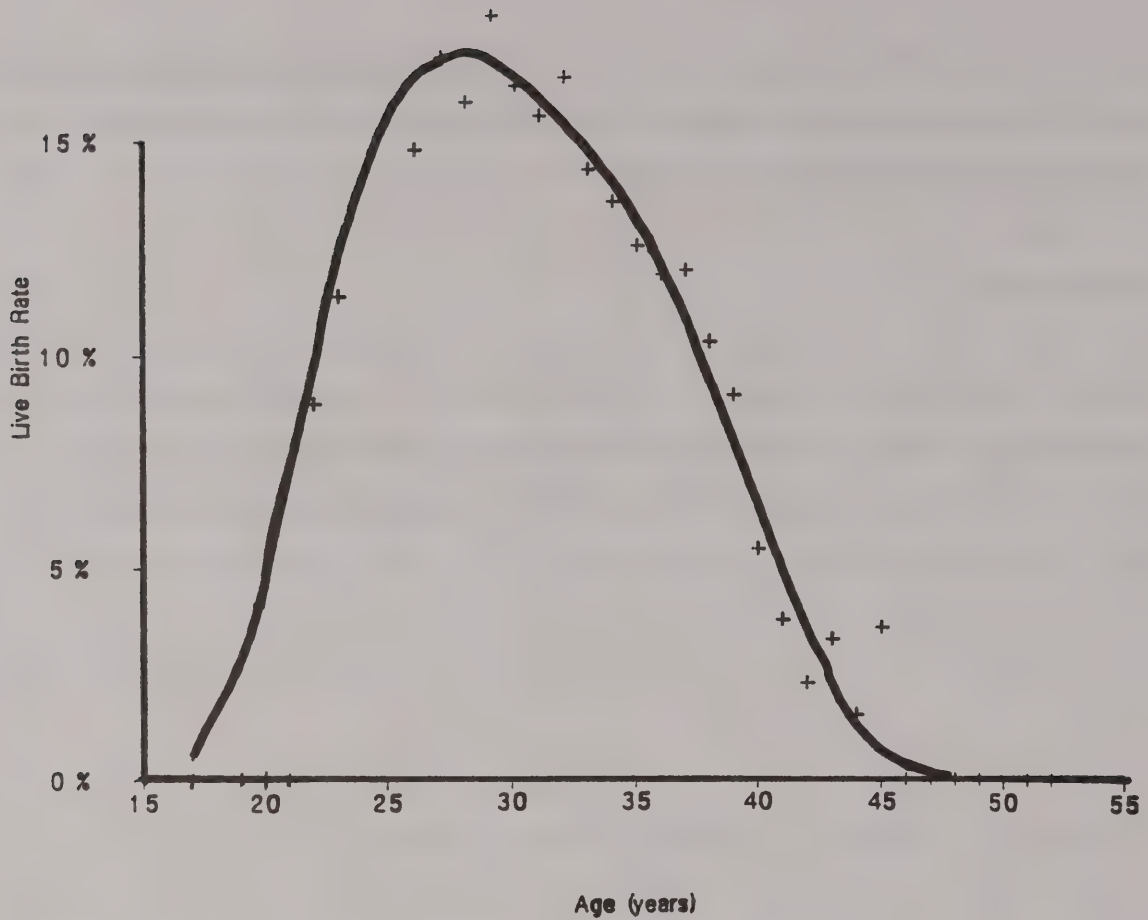


Figure 1
Success of IVF Treatments by age in 1992 (%live birth rate per treatment cycle)

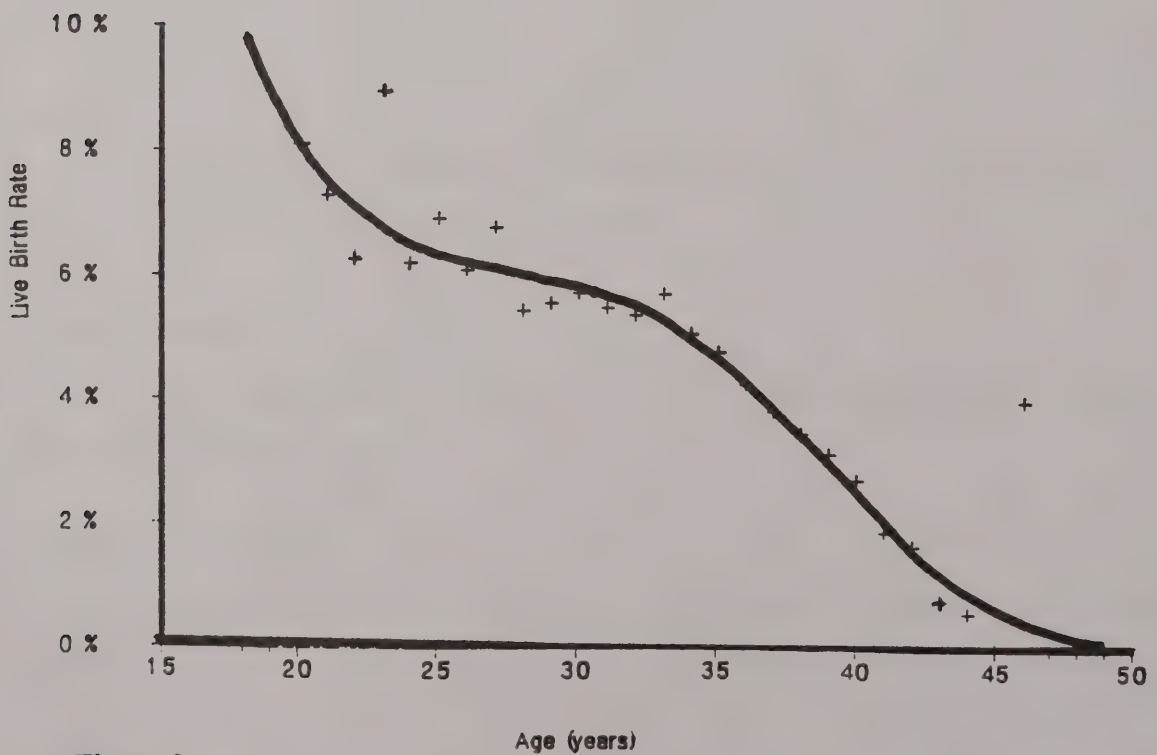


Figure 2
Success of DI Treatments by age in 1992 (%live birth rate per treatment cycle)

THE HUMAN FERTILISATION & EMBRYOLOGY AUTHORITY

DRAFT

TREATMENT CENTRE: QUESTIONS TO ASK

Introduction

This leaflet aims to help people seeking fertility treatment to understand the services offered by specialised fertility centres and to help them choose the treatment centre that is best for them.

Many people seeking fertility treatment will have discussed their fertility problems with their GP and may have been examined by an obstetrician or gynaecologist at a hospital. Some may have had tests to determine the cause of their infertility. They may then wish to approach a specialised centre or centre which offers assessment, testing and treatment for IVF (in-vitro fertilisation or the 'test tube baby' technique) or treatment using donated eggs or sperm.

The Human Fertilisation & Embryology Authority (HFEA) is responsible for regulating and licensing centres which provide IVF and any treatment involving donated sperm or eggs. To obtain a licence a centre must comply with the requirements of the Human and Fertilisation and Embryology Act 1990 and with the HFEA's Code of Practice. All licensed centres must keep to these standards but the type and range of services they offer may differ widely.

The aim of this booklet is to assist people in their decision on choosing a centre by giving relevant background on the treatments themselves, on the general expectations that people should have, on the factors that will affect outcome, and on other factors that might be considered before deciding which centre to attend.

General advice on choosing a centre

No single treatment centre will be best for everyone. When considering treatment it may be advisable to approach several centres and make a comparison of the services they offer. There are also practical considerations to take into account. These include costs, the length of a centre's waiting list and the travelling involved. It may be useful for people seeking treatment to decide which factors are most important to them and form a list of priorities.

Success of IVF treatment

The average success rate of IVF nation-wide in 1992 was 13% live birth rate per treatment cycle commenced. The average live birth rate for donor insemination (DI) was 5% in 1992. However, these are averages, and the particular circumstances of each couple will determine the likelihood of success in their case. Many factors are involved, and for some the chances of success will be a little higher than this; for some it may be somewhat lower.

The kind of thing that will affect outcome are:

- age of the patient(s)
- cause of infertility
- for IVF, the quantity and quality of sperm

The overall success rates achieved by particular centres may affect your chances, but there are many other issues to consider as well. Some of these are discussed in this booklet.

Questions to ask fertility treatment centres

This booklet suggests questions which may usefully be asked of centres and discusses the kinds of answers which centres may give in reply. The questions suggested here are not exhaustive and people seeking treatment should feel free to ask any questions which they consider important. It is essential that they understand fully the cause of their infertility so that they have reasonable expectations about how a particular treatment can help them. By asking centres about all aspects of treatment offered, people seeking treatment may be better able to form a picture of the service available and to make an informed choice of centre.

What services are available?

*** What tests can be carried out by the centre?**

Tests may include analysing the man's semen and the conditions of the woman's womb, fallopian tubes and cervical mucus. It is important that the causes of infertility are investigated thoroughly so that patients get the treatment which is most suitable for them. It may be caused by the male partner or by the female partner or by both partners.

If the cause of a couple's infertility has not been investigated, they may wish to ask whether a centre can carry out the necessary tests. If they know the cause of their difficulties they will be able to ask whether a centre can offer the treatment they require. Some infertility remains unexplained but may still be successfully treated.

*** What treatments are offered at the centre?**

Different types of fertility problems require different treatments and a licensed centre may offer one or more of those listed below. A clinician at a centre should be able to explain satisfactorily why a particular fertility treatment is recommended. Patients should be confident that the treatment they will receive is appropriate for their type of infertility before they decide to go ahead.

1. Donor Insemination

If a woman cannot conceive because of problems with her male partner, it may be suggested that the couple consider artificial insemination using donated sperm. Donor insemination can also be used if the male partner carries an inherited disease. Donor insemination involves the collection of sperm from a donor who has undergone health screening, and placing it in the woman's vagina, cervix (neck of the womb) or in the womb itself to achieve a pregnancy. Insemination into the womb (intra-uterine) has the greatest success and requires the most skilled technique. Centres vary in the way they provide treatment. The centre may suggest that the woman monitors her own menstrual cycle (period) at home to decide the best moment for insemination. They may expect her to attend the centre for a series of hormone tests to determine the best time for insemination, or they may propose that she takes drugs to control her cycle, so that they can fix the best time for insemination.

2. In-vitro fertilisation using the couple's own eggs and sperm

In-vitro fertilisation (IVF) treatment may be appropriate for example if a couple's infertility is caused by the woman's blocked fallopian tubes. This treatment involves retrieval of eggs from the woman's ovaries under sedation or general anaesthetic. These eggs are mixed with her male partner's sperm in a dish and placed in an incubator to produce an embryo, or, usually, several embryos. Up to three of these embryos are replaced in the woman's womb at one time so that one or more may implant and a pregnancy may develop.

Every month a woman's ovaries develop several egg follicles but only one of these becomes fully mature and releases an egg into the fallopian tube for possible fertilisation. Usually, IVF centres give the woman drugs which cause the ovaries to mature several eggs in one monthly cycle and these eggs are collected for use in treatment. Other centres prefer not to stimulate the ovaries but collect the one egg that is normally produced and this is called Natural Cycle IVF. People seeking treatment may wish to discuss with the centre the availability and implications of treatment with or without such drugs.

Two variations of IVF techniques called SUZI (sub-zonal insemination) and ICSI (Intra-cytoplasmic Sperm Injection) may be appropriate where the male partner has low fertility. With these, his sperm is injected directly into eggs previously retrieved from the woman.

3. In-vitro fertilisation using donated eggs, sperm or embryos

The same IVF treatment may be available using donated sperm if the male partner is infertile, or using donated eggs if the woman has, for example, ovulation problems. IVF treatment using donated embryos may be offered if both partners are infertile but the woman is able to carry a baby to full term. Availability of this treatment will depend on whether the centre has access to supplies of donated eggs and sperm and also if it has appropriate storage facilities.

4. GIFT using donated eggs or sperm

If tests establish that there is nothing wrong with the woman's fallopian tubes, or infertility is unexplained, GIFT treatment may be offered. GIFT stands for gamete intra-fallopian transfer and involves retrieving eggs from the woman, and replacing up to three of them with

sperm in the woman's fallopian tubes so that they will fertilise in the normal way. If necessary, this treatment can be carried out using donated sperm or eggs.

*** Does the centre offer storage facilities?**

During IVF treatment many embryos may be produced. A clinician is permitted to replace up to three embryos in a woman during any one monthly treatment cycle. To replace more would increase the likelihood of multiple pregnancy, which could be dangerous to the woman and to the babies she is carrying.

If the centre has storage facilities, spare embryos can be frozen for use in a later treatment cycle if required. This may avoid the need for repeated egg retrieval, sperm collection and fertilisation. Spare eggs from a GIFT cycle may be fertilised in a dish and frozen in the same way. Should the remaining embryos not be needed, they can be donated for the treatment of others or for research, or they can be discarded. The donors have the choice.

*** Does the centre specialise?**

Some centres specialise in particular fertility treatments or in treating particular types of infertility. Those seeking treatment may consider it worth finding a centre which specialises in the type of treatment they require. On the other hand, a centre which offers a variety of treatments may be able to offer the choice of a different approach if one sort of treatment is not successful. Patients may wish to bear these points in mind when choosing a centre.

Who are the donors of sperm and eggs?

Sperm donors are often recruited from the student population and also amongst men with families who wish to help others. Egg donors are usually women who have completed their families and are undergoing sterilisation, who are having IVF or GIFT treatment or who respond to publicity and wish to help others. Donors are screened for HIV and other diseases and are required to give a full medical history. Details of the donor's physical appearance are recorded. Centres usually try to match the physical characteristics of donors with the male or female partner whose eggs or sperm are to be replaced. People seeking treatment may wish to ask about the criteria a centre uses in its donor matching policy.

What information does the centre provide?

Each centre must supply written information about the services it offers and about the success rates which have been achieved. This literature should be comprehensive and easy to understand so that people seeking treatment know what is involved and what are the implications. Staff at a centre will explain any points which are unclear.

Before beginning treatment, people will be asked to give informed written consent to treatment. If they are to be donors or to have licensed fertility treatment they must also by law give written informed consent to the use and storage of their sperm, or use of their eggs, and also to the use and storage of any resultant embryos. They must also by law be properly informed before being asked to consent to disclosure of identifying information about their treatment, for example to a GP.

What counselling is available?

In addition to the consultation and to receiving information, people must by law be offered counselling before they give consent to the use or storage of their eggs or sperm. There is no obligation to accept offers of counselling but it can be a useful opportunity to discuss with an impartial person any concerns about the implications of treatment or infertility in general. It may also be useful to enquire who provides the centre's counselling and where, and whether separate charges are made.

*** Does the centre have a patient support group?**

Some centres have patient support groups which may be a useful source of information and reassurance about treatment provided at that centre.

Are there any restrictions on the patients treated?

*** What is the meaning of "the welfare of the child"?**

Before offering treatment, centres must take into account the welfare of any child who may be born or affected as a result. This means that centres should bear in mind the commitment of people seeking treatment to having and bringing up a child or children. The ages and medical histories of their families will be considered as will the needs of any child or children who may be born and the ability of the prospective parents or parent to meet those needs. Centres should also consider any risk of harm to the child or children who may be born, such as neglect or abuse, and effect of a new baby or babies upon any existing child of the family. In assessing prospective patients for treatment, centres will take this into account as well as the effects of the treatment on the patients' own welfare.

*** Are there any age restrictions at the centre?**

Some centres have an upper age limit (for example, 40 years) for women offered treatment. Such limits vary between centres and can depend on an individual woman's general health. Others as a matter of policy do not offer treatment to single women or to unmarried couples. Some centres can treat only one type of infertility.

People seeking treatment should bear in mind that the final decision on whether or not to offer treatment to a particular person rests with the doctor concerned.

What is the centre's success rate?

The HFEA collects data from all centres about the treatment cycles that they perform. This enables it to produce detailed information about the success rates which each clinic has achieved in the past. However, this is not always the most reliable way of deciding on which is the best centre for you - all of the above factors should also be considered. Also, the success rates are for all their patients, whereas each individual patient is different. Success rates can therefore only give a general guide and you should discuss with your specialist the likelihood of success in your own particular circumstances.

At the back of this booklet is a list of all licensed centres, with information including a success rate for each. This success rate has been adjusted to take account of the different types of patients which the centre has treated. This is because, for example, where one centre has treated a large number of older women, they are likely have a lower success rate than one treating younger women. In these circumstances it is difficult to draw conclusions about the success rates of the two centres. The tables in this booklet show figures which have taken account of these differences, and provide a meaningful comparison. Success in each centre can change over time. It is also important to remember that the other issues mentioned in this booklet should also be fully considered before any decision is made about which centre to attend.

The success rates in this booklet include details about the numbers of live births achieved in the period in question. This means that the information used can be up to two years old. Many centres will have seen improvements since that time, and you may wish to find out from the centres themselves what their more recent results have been. The Authority has given instructions to all centres on what information to give patients in these circumstances, and on how to present it. You can therefore ask centres for their last year's treatment information and success rates, and you will be able to compare directly one with another as they will be given in the same format. If you have any doubts about the figures given by a centre you can contact the HFEA.

What is the risk of a multiple birth?

There is a greater risk of a multiple birth (usually twins or triplets) when undergoing IVF treatment. A centre may discuss the prospect of transferring two embryos rather three (the maximum allowable number) in order to try to reduce this risk. There are many complications which may result from having triplets including a greater incidence of complications in labour and of premature birth. You should discuss the possibilities in your particular case with your consultant.

Is there a waiting list for treatment?

There may be a waiting list for a consultation appointment, and also a waiting list for treatment. For some treatments the waiting list may be longer than for others. For example there is often a long waiting time for treatment with donated eggs, which are in short supply.

How many times will I have to visit the centre?

Fertility treatment may require the patient to attend the centre several times in each treatment cycle. It may therefore be necessary to travel frequently and to take time off work. This may be a factor to take into account particularly when considering treatment at a centre located some distance away.

Some centres offer a service known as "transport IVF". This involves the woman having tests and the egg retrieval procedure at a hospital close to her home. The eggs are transported in

an incubator to an IVF unit where fertilisation and embryo transfer take place. This treatment may be more convenient for people who do not live near an IVF centre. People embarking on transport IVF should ensure that they receive information, an offer of counselling and give written consents. This must be done before preparation for the egg retrieval procedure just as they would if the full treatment was taking place at the IVF unit.

Environment

Many people like to know that they will feel comfortable in the centre and with the centre's staff. It should always be possible to visit one or more centres simply to get a feel for the way in which they manage the whole treatment process. You may wish to visit centres and to talk to their staff before deciding which one to attend for treatment. Most centres will be willing to allow you to do this, and you should feel free to decide against a centre having visited it in this way.

What is the cost of treatment and what is covered by the charge?

The cost of fertility treatment varies from centre to centre. Some centres operate under the NHS and offer treatment free of charge. Some are located on NHS premises but are funded separately and may make a charge for treatment, depending on how they are funded. In these circumstances the treatment is not NHS treatment. Each centre will be able to give information about its charges. Be sure that it is clear from the start whether or not you are receiving NHS treatment and, if there are charges, exactly what they cover. Most centres offer wholly private treatment.

The way in which centres list their charges varies. Some quote a standard amount for a complete treatment cycle. (Each attempt at achieving a pregnancy is called a treatment cycle.) Others list separately the charges for different tests, for the drugs required, for the various stages of treatment and for counselling. In order to make comparisons of charges it may be helpful to know that the figures quoted include everything required for a full treatment cycle. In addition it may be helpful to ask how much of the fee is refundable if a treatment cycle is abandoned through no fault of the patient. People should be aware that there is likely to be a charge for the storage of spare embryos following IVF or GIFT treatment.

What will happen if I get pregnant?

The extent to which centres remain involved after treatment will vary. Some centres may carry out a pregnancy test and some antenatal care, others discharge patients to the care of their own GP or consultant straightaway. These differences may be important to people seeking treatment. In any event, the centre needs to know the outcome of the treatment and will be able to offer advice and support.

What will happen if I don't get pregnant?

If the treatment does not lead to a pregnancy then there are several options. It may be useful to ask a centre how many cycles of treatment are given before there is further investigation of the cause of infertility or before patients are offered further advice or counselling. After discussing the matter, patients may decide to try again, to try a different type of infertility treatment or to have no further treatment. The staff at the centre and the patient's GP or consultant, if they have been informed of the treatment, will be able to offer advice and support.

Is further information available?

Information and advice about fertility treatment is available from a GP or consultant and the clinician, nurses and counsellor at a centre. Each centre produces its own patient information, describing the services available and explaining what is involved in treatment. In addition, information is available from self-help groups such as ISSUE (St George's Rectory, Tower Street, Birmingham B19 3UY, telephone: 021 359 4887, fax: 021 359 6357) and CHILD (Box 154, Hounslow, Middlesex, TW5 0EZ, telephone: 081 893 7110, fax: 081 890 4744).

Further information is available from the HFEA, including leaflets on

- the role of the HFEA,
- donor insemination treatment,
- becoming an egg or sperm donor,
- the legal aspects of sperm and egg donation,
- a list of centres, and
- copies of annual reports

can be obtained by contacting:

HFEA
Paxton House
30 Artillery Lane
London E1 7LS

Telephone: 0171-377 5077
Facsimile: 0171-377 1871

[Date - MM/YY]

Choosing a centre - patient's checklist

The following checklist identifies many of the areas that you may wish to consider before deciding which centre to attend. To help you decide, it may be useful to mark on this checklist your feelings about these areas in each of the centres that you approach.

	Centre 1	Centre 2	Centre 3
Location			
Services			
Specialisms			
Cost			
Limitations			
Waiting list			
Information			
Success rate			
Preference			

List of treatment centres licensed by the HFEA

The tables that follow give useful information about individual centres and are designed to be used with the patient information given in this booklet.

None of the figures quoted for each centre are applicable to individual patients. The figures are a guide to comparisons between centres. As a prospective patient it is your individual situation that will have the most effect on your chances of achieving a live birth.

For each centre the attached tables give details of the treatments which are available, the number of cycles carried out during the year [1993], the adjusted success rate (see page [21] of this booklet), and a number of other details about the centre. This section includes national averages for each of the figures given in the centre entries.

More information will be available from the centres themselves. This might include more recent pregnancy and live birth rates which will be given in a standard format which will be set by the HFEA. If you have any doubts about figures given by the centre, you may contact the HFEA.

List of treatment centres licensed by the HFEA

All figures are for women aged under 38 yrs, using their own eggs unless otherwise stated.

Centre 1002	Treatment Cycle Information	
Assisted Fertility Unit	<i>In Vitro Fertilisation (IVF) Cycles</i>	
Dept of Obstetrics & Gynaecology	Total number of treatment cycles for all women	766
Falmer Hospital	*Adjusted Live Birth Rate	21%
Ringmer Road	% Abandoned Cycles	12%
Gillingham	% Multiple Births	31%
	% Unknown outcomes	6%
Tel 1976 456732	% women aged 38 yrs or more	38%
Private & NHS	<i>Donor Insemination (DI) Cycles</i>	
Licensed for:	Total number of treatment cycles for all women	174
In Vitro Fertilisation	**Adjusted Live Birth Rate	16%
Storage of Embryos	% Unknown outcomes	8.1%
Egg Donation	% Multiple Births	5%
Donor Insemination	% Women aged 38 yrs or more	3%

* Rate could vary by plus or minus 2.9% (95% Confidence Interval)

**Rate could vary by plus or minus 5% (95% Confidence Interval)

Centre 1005	Treatment Cycle Information	
Assisted Fertility Unit	<i>In Vitro Fertilisation (IVF) Cycles</i>	
Dept of Obstetrics & Gynaecology	Total number of treatment cycles for all women	852
Falmer Hospital	*Adjusted Live Birth Rate	21%
Ringmer Road	% Abandoned Cycles	19%
Gillingham	% Multiple Births	14%
	% Unknown outcomes	7%
Tel 1976 456732	% women aged 38 yrs or more	8%
Private only	<i>Donor Insemination (DI) Cycles</i>	
Licensed for:	Total number of treatment cycles for all women	258
In Vitro Fertilisation	**Adjusted Live Birth Rate	14.3%
Storage of Embryos	% Unknown outcomes	4.7%
Egg Donation	% Multiple Births	3%
Donor Insemination	% Women aged 38 yrs or more	8%

* Rate could vary by plus or minus 2.7% (95% Confidence Interval)

**Rate could vary by plus or minus 4.2% (95% Confidence Interval)

Data in tables is for example only. All centre details are fictional.

List of treatment centres licensed by the HFEA

All figures are for women aged under 38 yrs, using their own eggs unless otherwise stated.

Centre 1089	Treatment Cycle Information	
	<i>In Vitro Fertilisation (IVF) Cycles</i>	
Assisted Fertility Unit	Total number of treatment cycles for all women	73
Ringmer Hospital	*Adjusted Live Birth Rate	12%
Farmer Road		
Basildon	% Abandoned Cycles	16%
	% Multiple Births	26%
Tel 1976 456732	% Unknown outcomes	2%
	% women aged 38 yrs or more	20%
Private & NHS		
	<i>Donor Insemination (DI) Cycles</i>	
Licensed for:	Total number of treatment cycles for all women	1821
In Vitro Fertilisation	**Adjusted Live Birth Rate	6%
Storage of Embryos		
Storage of Sperm	% Unknown outcomes	3.3%
Egg Donation	% Multiple Births	13%
Donor Insemination	% Women aged 38 yrs or more	2%
Zygote Intra Fallopian Transfer		

* Rate could vary by plus or minus 7.5% (95% Confidence Interval)

**Rate could vary by plus or minus 1.1% (95% Confidence Interval)

Centre 1092	Treatment Cycle Information	
	<i>In Vitro Fertilisation (IVF) Cycles</i>	
Infertility Unit	Total number of treatment cycles for all women	126
Dept of Obstetrics & Gynaecology	*Adjusted Live Birth Rate	12%
Rodean Hospital		
Powell Road	% Abandoned Cycles	29%
Maidstone	% Multiple Births	29%
	% Unknown outcomes	8.9%
Tel 1976 456732	% women aged 38 yrs or more	15%
Private Only		
	<i>Donor Insemination (DI) Cycles</i>	
Licensed for:	Total number of treatment cycles for all women	331
In Vitro Fertilisation	**Adjusted Live Birth Rate	6%
Storage of Embryos		
Egg Donation	% Unknown outcomes	7.8%
Donor Insemination	% Multiple Births	12%
	% Women aged 38 yrs or more	10%

* Rate could vary by plus or minus 5.7% (95% Confidence Interval)

**Rate could vary by plus or minus 2.6% (95% Confidence Interval)

Data in tables is for example only. All centre details are fictional.

List of treatment centres licensed by the HFEA

All figures are for women aged under 38 yrs, using their own eggs unless otherwise stated.

Centre 1143	Treatment Cycle Information	
Infertility Centre	<i>In Vitro Fertilisation (IVF) Cycles</i>	
Hughes Hospital	Total number of treatment cycles for all women	158
Basildon Road	*Adjusted Live Birth Rate	4%
London	% Abandoned Cycles	28%
Tel 1677 777732	% Multiple Births	25%
Private & NHS	% Unknown outcomes	11%
	% women aged 38 yrs or more	26%
Licensed for:	<i>Donor Insemination (DI) Cycles</i>	
In Vitro Fertilisation	Total number of treatment cycles for all women	115
Storage of Embryos	*Adjusted Live Birth Rate	4%
Egg Donation	% Unknown outcomes	12.1%
Donor Insemination	% Multiple Births	3.9%
	% Women aged 38 yrs or more	13%

* Rate could vary by plus or minus 3.1% (95% Confidence Interval)

**Rate could vary by plus or minus 3.6% (95% Confidence Interval)

Centre 1146	Treatment Cycle Information	
New Fertility Clinic	<i>In Vitro Fertilisation (IVF) Cycles</i>	
Keats Hospital	Total number of treatment cycles for all women	102
Gunn Road	*Adjusted Live Birth Rate	4%
West Kennet	% Abandoned Cycles	27%
Tel 1222 539832	% Multiple Births	20%
Private & NHS	% Unknown outcomes	6.5%
	% women aged 38 yrs or more	15%
Licensed for:	<i>Donor Insemination (DI) Cycles</i>	
In Vitro Fertilisation	Total number of treatment cycles for all women	543
Storage of Embryos	**Adjusted Live Birth Rate	4%
Egg Donation	% Unknown outcomes	7.2%
Donor Insemination	% Multiple Births	7%
	% Women aged 38 yrs or more	12%

* Rate could vary by plus or minus 3.8% (95% Confidence Interval)

**Rate could vary by plus or minus 1.6% (95% Confidence Interval)

Data in tables is for example only. All centre details are fictional.

National Data

All figures are for women aged under 38 yrs, using their own eggs unless otherwise stated.

National Averages: Treatment Cycle Information (1992 data)	
<i>In Vitro Fertilisation (IVF) Cycle</i>	
Total number of treatment cycles for all women	18,224
Adjusted Live Birth Rate	14.6%
% Abandoned Cycles	23.9%
% Multiple Births	30.2%
% Unknown outcomes	8.4%
% treatment cycles for women aged 38 yrs or more	22.2%
<i>Donor Insemination (DI) Cycles</i>	
Total number of treatment cycles	26089
Adjusted Live Birth Rate	5.5%
% Unknown outcomes	8.1%
% Multiple Births	7.9%
% treatment cycles for women aged 38 yrs or more	12.4%

Glossary of terms

TERM	DEFINITION
Clinical Pregnancy	Ultrasound evidence of a fetal heart.
Donor Insemination (DI)	The insemination into a woman of donor sperm (at the cervical opening or into the cervical canal).
Ectopic Pregnancy	Pregnancy (sac) outside the uterus.
Egg Collections	Successful egg collection procedure.
Embryo Transfer	Transfer of one or more embryos to the uterus. Three embryos is the maximum allowed by law.
Endometriosis	Endometrial cells, which normally line the uterus, implant around the outside of the uterus and/or ovaries.
Female Factor	This term covers any reason why a woman is infertile, such as ovulation failure or damage to the fallopian tubes.
Gamete	The male sperm or the female egg.
GIFT	Gamete Intra-fallopian Transfer. Sperm and a maximum of three eggs are transferred together to one or both of a woman's fallopian tubes. GIFT is a fertility treatment only licensed by the Authority if donor gametes are used.
In Vitro Fertilisation (IVF)	Sperm and eggs are collected and put together to achieve fertilisation outside the body. Up to three of the resulting embryos can be transferred into a woman's uterus.
Intrauterine Insemination (IUI)	The insemination into a woman of specially prepared sperm through the cervical canal into the uterine cavity.
Live Birth	The delivery of one or more babies.
Male Factor	This term covers any reason why the male partner's sperm may be less effective or incapable of fertilisation, ranging from a failed reversal of a vasectomy to the absence of viable sperm.
Miscarriage	Spontaneous complete loss of a pregnancy before 24 weeks.
Miscarriage Rate	Proportion of pregnancies which miscarry.
Multiple Birth	Birth of more than one baby from a pregnancy (these are counted as single live births irrespective of the number of babies).
Multiple Birth Rate	This rate is calculated as a proportion of all multiple births.

Multiple Pregnancy	Presence of two or more fetal hearts in a pregnancy.
Multiple Pregnancy Rate	This rate is calculated as a proportion of all multiple clinical pregnancies.
Perinatal Death	The death of a baby either in the uterus after 24 weeks pregnancy (Stillbirth) or within one week after live birth.
Superovulation	The stimulation of a woman's ovaries with drugs to produce more eggs than usual in a monthly cycle.
Termination of Pregnancy	Induced loss of a complete pregnancy.
Treatment Cycle	a) IVF with fresh embryos: a cycle begins with the administration of drugs for the purpose of superovulation, or if no drugs are used, with the attempt to collect eggs. b) IVF with frozen-thawed embryos: a cycle begins with the removal of the stored embryos in order to be thawed and then transferred c) Abandoned Cycles: IVF Cycles which cease before transfer of the embryo. d) For DI, a treatment cycle begins when the first insemination with donor sperm takes place.
Unknown Outcome	The outcome of a clinical pregnancy is unknown due to incomplete information being returned by a centre.
Unstimulated ("natural")	No drugs were given to stimulate the cycle (see Superovulation).
Uterine Fibroids	Benign growths of fibrous connective tissue and muscle that develop within the uterine wall and sometimes interfere with the implantation of an embryo.

To: Directors of Centres
Consultation list

Ref: CH(95)1

19 January 1995

Dear Colleague

Publication of success rates - HFEA consultation

In our 1994 Annual Report the Authority said that it would "give further consideration to the best way of presenting comparative statistical information about the success of IVF and DI treatment at different centres". In the Foreword to that report my predecessor said that the Authority's objective was to "provide people with information which is both meaningful to them and fair to centres. We are determined to find a solution which is widely acceptable in the coming year".

We have given considerable thought to this issue over a number of months and we believe that we have found a way of presenting relevant information that meets both the criteria of usefulness and fairness. The enclosed consultation package sets out our thinking so far, and we would welcome your comments on these proposals before we make final decisions about how to proceed.

We start from the principle that where information is held, and when legitimate requests are made for it, it is right to give it unless there are compelling reasons not to do so.

There has been a clear and sizeable demand for centre-specific success rates from prospective patients, from patient groups and from parts of the media. We have looked at why such information is wanted, the way in which it might be presented, why it might be unhelpful or misleading, and the ways in which any such reservations could be overcome.

Broadly speaking, our conclusion is that this information should be given. While there are a number of variables affecting outcome which might make the comparison of success rates complicated, we can produce a model which adjusts for these variables sufficiently to make the exercise valuable.

Human Fertilisation & Embryology Authority
Paxton House, 30 Artillery Lane
London E1 7LS

Telephone: 0171 377 5077
Fax: 0171 377 1871

Chairman: Mrs Ruth Deech
Chief Executive: Mrs Flora Goldhill

However, we also recognise that even if success rates can be fairly presented, they still form only a part of the picture that patients should consider when they come to choose a clinic. We would aim therefore to set success rates clearly in the context of a wider and more general set of information for patients. This is reflected in the enclosed consultation package.

The package consists of the following:

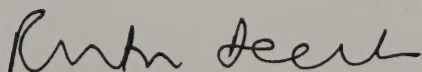
- consultation paper outlining the Authority's views and raising questions on which comments are sought;
- explanation of the basis of the proposed statistical model for analysing and presenting centres' success rates;
- draft patient information booklet showing the context in which success rates would be presented; and
- presentation of anonymised success rates for several IVF and DI clinics; and

We would welcome comments on the specific questions raised in the consultation paper itself. In addition, we would be grateful for comments on the draft patient booklet and any detailed comments or suggestions in respect of the statistical model.

Licensed centres already give patients details of their own success rates, and have always done so. It is right that they should do this, but our experience is that centres present these data in different ways and at different times. Patients therefore currently receive inconsistent information. Our aim is to give them access to information that is clear, fair and consistent. We appreciate that it is difficult to find a way of presenting these data in a way that is consistent, meaningful, and acceptable to everyone. However, information should be given, and we are seeking a way of ensuring that it is as honest and as helpful as possible.

The enclosed package sets out what we believe to be the best way forward. We would be grateful to receive your comments by 31 March 1995.

Yours sincerely



Mrs Ruth Deech
Chairman

